

## Continuity of Care Invaluable for Supporting a Family's Caregiving

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"A neurologist diagnosed my husband (AC) of 31 years with dementia in 2007, at the age of 64. The medical report stated that Alzheimer's Disease was the likely cause of the dementia. This diagnosis left our family with many questions that his neurologist and physician were not able answer.

Thankfully, shortly after his diagnosis, we were referred to Helen Davies and the Stanford-Palo Alto CADC as a resource. After an in-depth behavioral examination and careful review of his medical records, Helen and her team were able to refine my husband's diagnosis to Frontal Temporal Lobe Degeneration (FTD). The refined diagnosis of FTD was very important and valuable to our family because it explained why my husband was experiencing changes in his behavior. Helen and her team continue to perform a comprehensive neurological examination of my husband every year, which gives our family information on how the disease is progressing and in turn allows us to provide better care for him.

As the disease has progressed, it has brought with it many unexpected challenges. Helen has given my family and other caregivers like myself the time we need to discuss dementia-related problems we have observed with our loved ones. Most recently, Helen took the time and explained to me what she thinks of the recent onset of jerking movements my husband has experienced, and how these are characteristics of Alzheimer's progression.

In addition, I was alarmed when my husband recently gained 20 lbs in 4 months after he started taking an anti-anxiety medication. I explained the weight gain to a neurologist and a geriatric psychiatrist, they could not tell whether the weight gain was a result of the disease, a side effect of his new medication, or if there was potentially another cause we should explore. I met and spoke with Helen about my husband's weight gain. She said it might be a result of hyperorality-induced cravings caused by FTD, and not necessarily only a side effect of the new medication. This information was an important factor in deciding whether to continue the new medication and also gave me options that might help my husband satisfy his constant cravings in a low-calorie way that would not further affect his weight and overall health.

Helen offers solutions and recommendations that help me to continue growing in my knowledge so that I am better able to provide the best care to my husband at home. Helen has been able to put a framework around the total person. This has helped me become a more effective and compassionate caregiver to my husband, as well as a resource to my family and other caregivers."

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